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Writing Factsheets That
Patients Can Read and Use

Purpose: This tool provides guidelines and tips on writing factsheets for patients and family members. It explains how factsheets are translated for these audiences and the organizational template used for factsheets published by the MSKTC.

Format: The tips are presented in a concise bulleted format for easy use. The list also contains additional resources for presenting data creatively.

Audience: This tool is designed primarily for researchers from the Model Systems that are funded by the National Institute on Disability and Rehabilitation Research (NIDRR). The tool can be adapted by other NIDRR-funded grantees and the general public.

Guidelines for Writing Patient Factsheets

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What can writers do to ensure that factsheets make a difference for patients and family members?

1. **Develop a clear purpose for the Factsheet.**

> ### Why Does Your Patient or His or Her Family Member Need a Factsheet?
>
> - To understand what is happening to my body right now and what is causing it to happen.
> - To understand my body and any medical terms about my injury so that I can communicate effectively with my doctors and other clinicians.
> - To understand what options are available to me and where my choices are limited—especially what is in my control and what is not.
> - To understand the tradeoffs and choices of action that I or my doctor can take to address the issue or problem well enough to make a decision about what I or my doctor should do.

Readers should be able to easily identify the purpose of the handout and what they can do with the information.

2. **Determine the content in the factsheet.**

Include information to help users make decisions or take actions. Factsheets should include essential information only—what will help a patient or family member make a specific decision or take a specific action?

- A large amount of information can overwhelm a patient or family member, stopping the person from reading and understanding. Therefore, information should be presented around a single, focused scenario that involves an immediate action or decision. Future outcomes, actions, or decisions should be separated into other documents. Focus should be placed on what can be done to alleviate the problem rather than on the problem itself. For most audiences, this rule applies: "Never tell me something that I can't do anything about."
- Information should be **action-oriented** whenever possible, presented in terms of actions taken by a clinician, patient, or family member to address the medical need. For example, a factsheet discussing an effect of the injury (such as bowel dysfunction) should focus on the steps taken to manage the effect and reduce its impact rather than focusing on the effects of the injury on normal function.

Strategize around the emotional impact of the text. Writers should be aware of potential emotional reactions to the amount or nature of information that may affect motivation to continue reading and/or act upon the information provided. Writers should remember that patients and family members will not view information objectively, but through an emotional lens.

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- Writers should recognize and limit "worry-producing" content. Traditional medical communication assumes that if a medical possibility exists (a negative outcome, adverse effect, and so on.), then it should be communicated. However, content that may be scientifically accurate but is based on limited probability (possible but not probable) increases patient or family member worry and limits comprehension and decisionmaking, particularly if the patient or family member has no control or action to mitigate the outcome. Therefore, information on possible negative outcomes that are worthy of warning is best presented as "things to watch for," with a presentation of symptoms and clear instructions on next steps ("contact your doctor").

> **Avoiding Negative Reactions to Information**
>
> - Qualifiers should be used such as "for most people" or "sometimes"
> - Avoid contradictions in statements of efficacy or adverse effects such as "This will help you. . . when it does not help you. . ."
> - Writers should avoid "scare tactics" to increase adherence. Evidence suggests that these have limited effectiveness, particularly in individuals who are at heightened emotional stress.

- Information should be presented in a way that increases patient or family member self-efficacy. This includes positive coping approaches to outcomes that are outside the control of the patient or family member.
- Information that is unavoidably negative should be tempered with statements concerning positive coping or encouragement. For example: "While this may be challenging to accept, it is important to know that many people with (condition or outcome) are able to manage this challenge and still lead happy, productive lives."
- Occasionally, acknowledging a negative reaction is appropriate and can assist with removing blocks to reading and information intake. These statements should always be followed by statements of encouragement or some action to address the emotion.

> **Examples of Statements of Encouragement**
>
> - "Having limited ability can be frustrating and may make you feel overwhelmed. It may be important to talk to someone such as a family member, close friend, or a counselor about these feelings."
> - "(Function loss or Outcome) can be embarrassing or make you feel isolated. However, many people have found ways to overcome these feelings. . ."
> - "Thinking about these possibilities can be frightening. However, being aware of possible problems gives you the best chance of avoiding them or acting quickly to reduce their impact."

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3. **Use a plain language writing style.**

Writers should be conscious of writing style. Traditional medical writing can be hard for people to understand. If you want people to use the information, write in plain language. The MSKTC will help with this process, but you can also assist this effort:

- Use plain language to make information more accessible. Plain language is not "dumbing down," and it is not just about reading level.
- Plain language is more than words. It focuses on helping readers quickly and easily
  - Find what they need;
  - Understand what they find; and
  - Act appropriately on that understanding.
- Following are general guidelines for plain language use:
  - Medical terminology should be used sparingly and only to assist patients if they are likely to encounter it in a clinical setting.
  - References to anatomy or physiology should be defined and pictured before being used.
  - Complex concepts should be broken down and reduced to simple terms. Simple, everyday words should be used in place of technical jargon.
  - Analogies and metaphors should be used to express concepts and processes. Analogies should be based on common, everyday objects and functions that cross ethnic, generational, or gender boundaries. Ethnocentric analogies and metaphors should be avoided.
  - Sentences should be short and constructed in simple, active voice: Noun, verb, adjective, and/or adverb.
  - Use present tense whenever possible.
  - Bullets should be used in place of long blocks of text.
  - Avoid dependent phrases and complex sentence construction.
  - Use pictures and simple diagrams whenever possible to express a term, process, or concept.
  - Use the second-person narrative ("you") when appropriate so that the factsheet is speaking directly to the patient or family member.

An Example of Plain Language Translation

Original Text:

The objectives of rehabilitation after an individual has sustained an acute spinal cord injury include maximizing the patient's medical, functional, and psychosocial outcomes, with functional outcomes being tied to the level of the individual's SCI.

Plain Language Translation:

Rehabilitation after a serious spinal cord injury works to help you make the most of:

- Your physical health.
- Your ability to do the things that matter to you.
- Your ability to interact with others.

The amount that rehabilitation can accomplish toward these goals depends on the type and seriousness of your injury.

- Reading level goal: sixth to eighth grade as determined by the Flesch-Kincaid Grade Level Test. *Note:* This test is based on number of syllables per word and number of words per sentence. Therefore, the use of most medical terms will increase the grade level. This may be unavoidable. Text surrounding the medical terms, however, should be at grade level.

- Readability goal: 75 or higher. *Note:* This test is based on number of syllables per word and number of words per sentence. Therefore, the use of most medical terms will reduce the readability score. This may be unavoidable. Text surrounding the medical terms, however, should be at highest readability possible.

4. **Organize the content in a way that is clear to the reader.**

The organization of content is critical to reader comprehension. The template for the MSKTC factsheets lays out information for users in a way that helps them understand what to know and do about the information. Although this format can vary from factsheet to factsheet, it may help to follow this template:

- **What is the TOPIC?** The beginning text should provide a context for the information, identifying the topic and purpose of the factsheet. This is provided in the upper left column of the factsheet. Remember that the topic should be action oriented and focus on the solution rather than the problem.

> **The MSKTC Factsheet Organizational Template**
>
> - **This factsheet explains. . . (introduction of topic)**
> - **"What You Need to Know"** (bullet summary of content)
> - **Content Sections as Questions in Information Breakdown Sequence**
> - **Summary Paragraph**

- **What is the TAKEAWAY?** The factsheet begins with a set of summary bullets titled "What You Need to Know." This summarizes the key "take away" points of the entire factsheet without detail.

- **What do the WORDS MEAN?** The section helps readers understand the terms or concepts explained in the factsheet. Therefore, the section "Understanding Your Body" follows with any references to anatomy or physiology that may be unfamiliar to the audience. These are defined and illustrated and can be used as a reference for readers as they read the remaining document.

- **What QUESTION does this ANSWER?** Information in the factsheet should be organized by a sequence of questions.

  i. "Why do I need to do this?" Describe the action in terms of the physical experience or potential problem it is trying to address, naming the problem by its medical term **only if necessary to receive further information or treatment.** You may need to explain the normal function first, but this is best done in the "Understanding My Body" section.

ii. "Why is it happening?" Explain the reasons for the physical experience or potential problem. How does my injury change my ability to function or cause this problem?

iii. "What exactly will this involve?" This may be a series of questions and answers in sequence to the self-management activity or clinical procedure in which each step is explained using terms that express the action **TO** or **BY** the individual. Remember, as medical devices or other terms appear in these explanations, they also need simple definitions.

iv. If the factsheet describes a self-management practice, it is important to be specific in answering the question, "What exactly do I need to do when and how?"

v. "How will I know it is helping?" There may be a need to explain intermediate and ultimate outcomes so that a patient or family member is able to gauge progress or determine ineffectiveness. This may also involve answering the question, "How long will it take until I see an effect?"

vi. "What should I watch out for?" Potential adverse effects and negative outcomes should be expressed as signs or symptoms to be aware of or note. Most importantly, these signs and symptoms should be tied to specific actions, such as when to stop the activity, when to contact a medical professional, and so on.

vii. "What can I expect?" The factsheet may need to be clear about the outcomes of the self-management activity or clinical procedure in terms of establishing expectations for the patient or family member. Is this a one-time activity, or does it need to be repeated? How often? Is this something I'll need to do for a set period of time or for the rest of my life?

- **Where can I learn more?** It may be helpful to provide a place where additional information can be found.
- **Where does this information COME FROM?** Research suggests that audiences use this information to determine credibility and trustworthiness of the information. This includes the author's credentials and sponsorship. (Audiences are critical of commercial sources.)

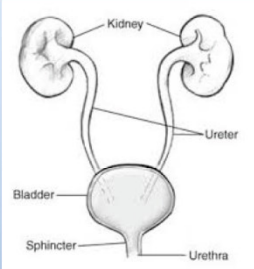5. **Find pictures and graphics to help the public understand.**

Pictures are the best way to communicate information to most audiences. However, images, like words, need context to communicate meaning.

- Anatomical diagrams should show where the anatomy is located in the body by showing the anatomy within an outline of the body.
- Anatomical diagrams should be simple and easy to read.
- Use labels for only the items that are being discussed in the factsheet.
- Pictures of processes need directional indicators when possible. Several images in sequence may be needed.
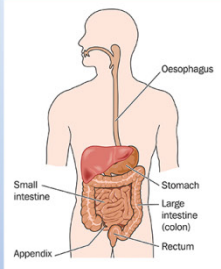
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- Images should be concrete and not conceptual. They should picture exactly what is being discussed.
- Images to support text evoke emotional responses as well. Avoid the use of photographs and use diagrams instead.

Effective and Ineffective Graphics

Reader doesn't know where anatomy is located.*   Better: Anatomy has physical context

Plain Language Resources

- "Plain Language Action & Information Network," includes "Writing User-Friendly Documents," http://www.plainlanguage.gov
- "CDC's Plain Language Thesaurus for Health Communications," http://www.plainlanguage.gov/populartopics/health_literacy/index.cfm (fifth item under "Federal Agency Links about Health Literacy")
- "Simply Put," Centers for Disease Control and Prevention, http://www.cdc.gov/healthliteracy/pdf/Simply_Put.pdf

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* Image from National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health.

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